

# Parental Uncertainty

## Parents' perceptions of health-related quality of life in newly diagnosed children with cancer

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**BACKGROUND:** Parents of children with cancer are predisposed to psychological distress symptoms, such as anxiety, depression, and uncertainty. This vulnerability may exacerbate underlying mood disturbances, including trait anxiety and depression, and influence parents' perception of health-related quality of life (HRQOL) in their children.

**OBJECTIVES:** This study examined the relationship between parental uncertainty and parent proxy reports of HRQOL in newly diagnosed children with cancer.

**METHODS:** A longitudinal descriptive approach was used to examine the relationship between parental uncertainty and parent proxy reports of HRQOL in 55 parent-child dyads. Parental trait anxiety, depression, and perceived social support were evaluated as potential predictor variables.

**FINDINGS:** Parents of newly diagnosed children with cancer reported lower parent proxy HRQOL scores. Parental uncertainty was prevalent and affected parents' perceptions of HRQOL three months following diagnosis; however, higher social support scores buffered these negative effects.

### KEYWORDS

health-related quality of life; uncertainty; depression; anxiety; social support

### DIGITAL OBJECT IDENTIFIER

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**DESPITE ADVANCEMENTS IN CARE AND IMPROVED SURVIVAL RATES**, adverse effects from treatment for childhood cancer can lead to substantial distress in children and their families (American Cancer Society [ACS], 2017; National Cancer Institute [NCI], 2019). Adverse effects from cancer treatment have been linked to impairments in multiple dimensions of health-related quality of life (HRQOL) in children with cancer (Baggot et al., 2011; Dietz & Mulrooney, 2011), as well as parental psychological distress and maladjustment (Mullins et al., 2012). Patient-centered outcomes in HRQOL are critical to pediatric cancer care and research (Rosenberg et al., 2016).

Previous research has shown that psychosocial distress is prevalent in parents of children with cancer (Fedele et al., 2013; Wakefield, McLoone, Butow, Lenthen, & Cohn, 2011). The incidence range of psychological distress symptoms is estimated at 10% to 41% from initial diagnosis through remission and relapse (Dunn et al., 2012). In a study by Wikman, Mattsson, von Essen, and Hoven (2018), five years after the completion of treatment or the child's death, anxiety and depression were reported in 30% and 35% of parents, respectively. As a result, parents of children with cancer may be predisposed to symptoms of anxiety, depression, and uncertainty (Pöder, Ljungman, & Von Essen, 2010; Rodriguez et al., 2012). Uncertainty can be a predictor of distress in parents of children with cancer (Lee, Gau, Hsu, & Chang, 2009), is strongly associated with mood disturbances (Taylor-Piliae & Molassiotis, 2001), and can affect the ability of parents to adapt to their child's diagnosis (Mullins et al., 2012).

Parent proxy (parental reporting of children's responses to treatment and illness) is prone to reporting bias, particularly among parents who are in psychological distress. For example, parents who have a history of anxiety or depression are more likely to report lower HRQOL scores in their children with cancer as compared to parents who do not have a history of anxiety or depression (Lindahl Norberg, Pöder, Ljungman, & von Essen, 2012). Similarly, parents with decreased uncertainty and distress are more likely to report higher HRQOL scores in their children with cancer as compared to parents with increased uncertainty and distress (Liu & Yeh, 2010).

The Roy Adaptation Model (Roy & Andrews, 1999) and Mishel uncertainty in illness theory (Mishel, 1981) served as theoretical frameworks for this study.